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ABSTRACT

This report provides an overview of the Collaborative Study of Children with Special Needs, documenting the range of health and special education services provided for disabled students under the Education For All Handicapped Children Act. The study included surveys and interviews with parents of 2,000 disabled school children in five large United States school districts: Charlotte-Mecklenburg, North Carolina; Houston, Texas; Milwaukee, Wisconsin; Rochester, New York; and Santa Clara County, California. Teachers for 1,000 of the students were also surveyed. The study found that, in general, parents are satisfied with the services their disabled children receive, the vast majority of disabled students attend regular schools and spend at least part of the day in regular classes, the percentage of the elementary school population deemed eligible for special education ranged from 7.6% to 13.4%, and the socioeconomic status of the special education children mirrored that of the total school population in each district. On the negative side, the report concludes that: fewer than half of the parents participate in decisions about the services their children receive; physicians rarely participate in decisions about placement or services; few after-school, summer, or day care programs are available; and children with mild mental retardation or emotional disturbance remain in a "gray area" where their needs are neither well-defined nor well-served. (JDD)

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Number One 1988

Serving Handicapped Children:

A SPECIAL REPORT

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We embarked on the Collaborative Study of Children with Special Needs in 1982, out of a long-standing concern by the foundation for the health and well-being of children and their families. We believed that a progress report on the Education for All Handicapped Children Act, PL 94-142, one of the most important federal laws affecting children in the past decade, was extremely important. We wanted to know what difference the law had made in the lives of handicapped children, their families, their teachers, and their non-handicapped schoolmates.

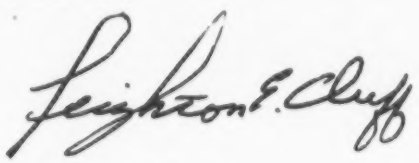
A landmark piece of legislation when it was enacted in 1975, PL 94-142 was notable for its exemplary effort to give children the services they need, not just what school districts were prepared to offer; for its insistence on the involvement of parents in making decisions about their handicapped children; and its requirement that health and other important supporting services be linked to the educational process.

PL 94-142 in large part resulted from parents' and professionals' deep concerns about the shortage of educational opportunities for handicapped children. It also grew out of the civil rights movement and was rooted in American values regarding equity. The law established the principle that children who are handicapped and children who are not are equally entitled to a free, appropriate education provided by their local public school systems. It said that, to the fullest extent possible, children with disabilities should be educated in the "least restrictive environment."

The notion of educating handicapped youngsters in the public education system was not new in 1975; special education was already an important part of the public schools. However, the law posed significant challenges for schools and communities that had not previously accommodated children across the wide spectrum of educational, developmental, physical, and emotional disorders. The implementation of PL 94-142 also presented considerable challenges for handicapped children and their families, although many welcomed those challenges along with the opportunities and benefits they implied.

This report cannot fully summarize the findings of this complex study. Rather, it is an overview of a large body of work that addresses many forces shaping handicapped children's lives — their schools, their families, their therapists, and their physicians.

A special word of appreciation should be extended to the five school systems who gave the study team extraordinary cooperation. Even more, we owe a debt to the researchers under the able direction of John A. Butler, EdD, and Judith S. Palfrey, MD, who have done a remarkable job in designing and conducting this study and whose dedication to the fortunes of children inspired this valuable work.



Leighton E. Cluff, MD
President
The Robert Wood Johnson Foundation

Federal Law Guaranteeing Handicapped Children a Free and Appropriate Public Education Successful in Transforming Local School Programs

Procedural guarantees are in place; a variety of health-related and other supporting services are available and used, even though collaboration with non-school medical providers remains weak; evidence on the effectiveness of special education is difficult to obtain, but some important indicators are positive.

Summary

The five-year Collaborative Study of Children with Special Needs documents the fact that the procedural guarantees of PL 94-142 are now securely in place, largely because our schools initially decided to grant special education relatively high status within their administration and because schools recognized that as many as 10 percent of children nationwide have special education needs.

The law's procedural guarantees have been translated into services for children with varying degrees of success. The study examined the services that the schools provide and found that, in general,

- parents are satisfied with the services their disabled children receive
- schools are willing to serve as therapeutic agents
- schools are committed to the principle of serving disabled children in the "least restrictive environment."

On the negative side, challenges remain in the areas of the way children are classified, the services provided for emotionally disturbed children, and the need for greater involvement of health care professionals in the planning and implementation of services.

Perhaps today's largest and most important concern is whether special programs for handicapped children can be maintained against the onslaught of cost-containment pressures now facing school districts.

Specifically, data from the Collaborative Study show the following results:

- The special education population is extremely diverse. It includes not only large numbers of children who are categorized as learning disabled or speech impaired, but also children who are emotionally disturbed, mentally retarded, blind, deaf, physically handicapped, chronically ill, or multiply handicapped.
- The vast majority of special education students are "in the mainstream," attending regular schools and spending at least part of the day with a regular class.
- Because of marked differences in local practices and some real variation in incidence of various conditions, the percentage of the elementary school population deemed eligible for special education ranged from 7.6 percent in one of the districts studied to 13.4 percent in another. This difference is primarily attributable to differences in the ways communities classify mentally retarded, emotionally disturbed, and learning-disabled children.
- Once a child is found eligible, classification and placement decisions again differ according to state requirements, local and state traditions, professional attitudes, availability of services, and a host of other factors.
- Among the children with special needs, only 29 percent were diagnosed before age five. These children were primarily those with physical handicaps and vision/hearing disorders.
- Schools remain the major site of identification for most children with special needs. Nonetheless, physicians identified between 15 to 25 percent of the children with learning disabilities, speech impairments, emotional disorders, and hyperactivity.
- The socioeconomic status of the special education children mirrored that of the total school population in each district. Overall, minority groups accounted for over one-third of the special education students. Except in one relatively affluent site, more than one-third of the special education children were poor, and more than one-third of their mothers had not completed high school.

This Special Report *is based on the findings and experience of the researchers and school districts involved in the Collaborative Study of Children with Special Needs; interviews with study participants and observers; consultations with experts in child health and special education; and the published literature. Of particular help was the researchers' summary article on the implementation of PL 94-142, published in the* Harvard Educational Review, *May 1987.*

- Many therapeutic services are now provided in schools. Nearly half of all children in special education receive speech or hearing therapy, whereas physical and occupational therapy are concentrated on children with physical, vision/hearing, or health impairments, as well as on the mentally retarded.
- Most handicapped children have a regular source of health care, although they may not see the same physician at every medical visit. Gaps in access to health care exist for poor and minority children.
- While PL 94-142 intended that the development of a child's Individualized Education Program (IEP) involve parents, usually less than half actually attended their child's IEP meeting.
- Generally, parents are pleased with their children's school program and the services they receive, and the teachers are positive about the students' academic progress and social adjustment.
- On average, special education costs nearly twice as much per child as regular education.

The needs of many special education children and their families are so broad and complex that they go well beyond what schools can provide. Strong state Medicaid programs and strong mental health and child service agencies must pick up where the schools cannot.

While some of these findings undoubtedly correspond to the national experience, they are specific to the five sites studied and cannot be generalized to the country as a whole. They may more closely present the picture in the nation's large, urban school systems rather than in smaller districts or rural areas.

The study documents a large number of services being given and a high degree of satisfaction among parents, a group that only 13 years ago was vocal in its dissatisfaction with disabled children's educational opportunities.

Background

In 1974, the US Comptroller General sent Congress a report on handicapped children that painted a dismal picture indeed: 60 percent of the nation's handicapped children were not receiving appropriate schooling; one million handicapped children were excluded entirely from the public school system; only 16 states provided special education services to more than half of their school-age handicapped population; few districts provided educational services comprehensive and flexible enough to meet the needs of all handicapped children; existing special education programs were sometimes fragmented and uncoordinated; limited availability was compounded by restrictive eligibility policies; the lack of preschool services thwarted efforts at early intervention; and finally, few educational and vocational programs were designed to lead to career opportunities, an essential component of comprehensive educational services for the handicapped.[1]

Less than a quarter of handicapped children leaving school were expected to be fully employed, to go to college, or to participate in a sheltered workshop. Most would remain dependent on society throughout their lives, at a monetary cost of several billion dollars a year and an incalculable personal cost. Nevertheless, the GAO reported that educators believed "75 percent of the physically disabled and 90 percent of the mentally retarded could work if given the proper education and training."

The nation had already witnessed dramatic shifts in public attitudes and national policies toward children with handicaps. The Council for Exceptional Children and other groups were exerting pressure on the states and in Washington to expand and improve educational services for handicapped children. Many states were formulating their own guidelines for identifying and placing children with special needs within local public school systems, some of which were even stronger than the new federal law. The federal law, nevertheless, gave these initiatives more clout and visibility.

Congress passed the Education for All Handicapped Children Act of 1975 (PL 94-142) with record support. Hailed as "the single most important piece of federal education legislation enacted during the 1970's,"[2] the new law set the stage for strong federal leadership and provided many other states and local school districts the impetus they had awaited. The decade since its passage has been marked by declining tax revenues, increasing school costs, and widespread dissatisfaction about the quality of public education; yet the program still enjoys strong bipartisan support from Congress as well as from local school district leaders.

Programmatically, the schools are asked to undertake a substantial responsibility for the developmental welfare of handicapped children. They must: (1) identify all handicapped children and offer them educational services; (2) assess each handicapped child individually and formulate a written Individualized Education Program (IEP); (3) ensure that handicapped students are placed in the "least restrictive environment" commensurate with their needs; (4) notify parents in writing about identification, evaluation, and school placement of their child and establish grievance procedures for parents wishing to contest a district decision; and (5) provide those "related services" required for children to benefit from special education.

Marilyn West, Nursing Services Coordinator, *Santa Clara County Office of Education, is a favorite visitor among students at the Chandler Tripp School, which serves only children with multiple handicaps who are too limited functionally to attend class in a regular school. There's no such thing as "can't do" in Ms. West's approach to special education — anything and everything is worth a try.*

Footnotes

1. U.S., Comptroller General. Federal Programs for Education of the Handicapped: Issues and Problems. *Washington, DC: U.S. Government, 1974.*

2. Pittenger JC and Kuriloff P. Educating the Handicapped: Reforming a Radical Law. The Public Interest, *72-96, 1982.*

The extent to which that mandate is being met nationwide is documented in part in Annual Reports to Congress prepared by the US Department of Education, Office of Special Education and Rehabilitative Services. Nationally, the proportion of special education students grew from about eight to about 11 percent of the school population after the implementation of PL 94-142. Most of this growth was concentrated in two previously underserved groups at either pole of the disability spectrum. First was the relatively small number of severely handicapped children, who formerly had been institutionalized or kept at home and who previously had few or no educational opportunities; and second was the very large group of children in the "soft" learning disabled category. The number of children in this group — many of whom also previously would have been ineligible for special education services in the public schools — grew from 800,000 (2.2 percent of special needs students) in 1976-77 to 1.9 million (4.3 percent) nine years later.

The Department of Education reports do not reflect the great variation in local special education practices, nor do they explain what drives individual school districts towards one educational placement versus another. Moreover, they tell little about the classroom environments for special education students, or the needs of the handicapped children enrolled. Furthermore, policymakers, educators, health practitioners, and parents have had little data to determine whether PL 94-142 is, in fact, improving the lives of handicapped children or to document its effects on their families and non-handicapped peers.

In order to help fill these gaps in information, The Robert Wood Johnson Foundation, in conjunction with The Commonwealth Fund, in 1982 began funding for a multi-year study to examine the interface between health and education services for children with special needs. The study was to describe patterns of school placement, health services use, expenditures, service coordination, and — to the extent possible — educational and social outcomes for children in special education programs. The study, in which the two foundations invested more than $1.9 million, was directed by John A. Butler and Judith S. Palfrey, from The Children's Hospital Medical Center, Boston. An advisory committee, chaired by Julius B. Richmond, helped guide the study's progress.

Called the Collaborative Study of Children with Special Needs, this five-and-a-half-year research effort was conducted in five large metropolitan school districts: the Milwaukee Public Schools, the Houston Independent School District, the Charlotte-Mecklenburg Schools, the Santa Clara County (CA) Office of Education, and the Rochester (NY) City School District. These districts were selected because of their size (at least 18,000 elementary school students); their geographic, socioeconomic, and ethnic diversity; their sizable special education populations; and their high level of professional and parental interest in the coordination of health and educational services for handicapped children.

A carefully selected sample of more than 2,000 handicapped children representing the special education population was studied. The study involved reviews of school records and interviews

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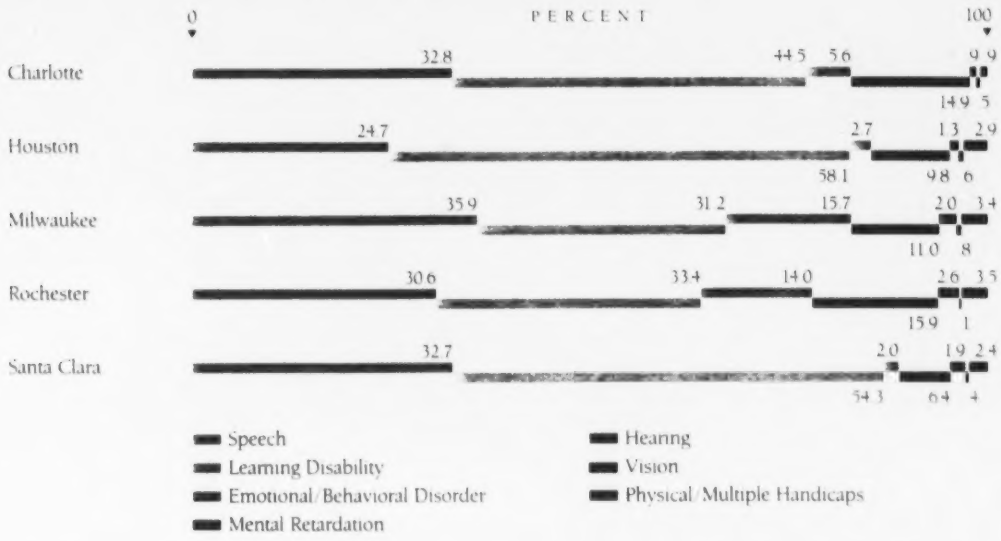
Figure 1. School Classification of Special Education Students' Disabilities



with parents and, for half of the children, teacher interviews as well. Parents and teachers were asked a wide range of questions about children's functional status, school placement, use of health and related services, and their own views on the children's school experiences. In each district, "key informants" were interviewed to gain information on school system dynamics.

Together, the five districts encompass a broad range of economic circumstances and educational policies. Compared to national averages, Rochester and Milwaukee spend higher-than-average amounts on education and identify a larger-than-average percentage of their student population as having special needs. Charlotte and Houston — somewhat more affluent communities — spend lower-than-average amounts on education and identify a smaller percentage of their student body as handicapped. Santa Clara County's consortium of 33 local school districts represents yet a different pattern. As the most affluent of the five communities studied, it spends average amounts on education and identifies a somewhat lower-than-average percentage of its student body as having special needs.

Study findings

Classification and Placement

Among sites included in the Collaborative Study, the percentage of elementary school children receiving special education services ranged from 7.6 percent in Charlotte to 13.4 percent in Rochester, falling well to either side of the national average of 10.7 percent.

The proportion of special needs children classified as having a particular handicap varies substantially across sites. (Figure 1) In several districts, proportionately fewer special education children were classified as emotionally or behaviorally disturbed, while in others this group accounted for 14 to 16 percent of the special education population. There were also marked variations among sites in the percentage of children classified as learning disabled or mentally retarded.

By contrast, the proportion of children given the more clear-cut classifications of hearing/vision disorders or physical/multiple handicaps were much more comparable and lower in numbers across the sites. Children who were hearing or vision-impaired, chronically ill, or who needed wheelchairs, braces, or crutches — the disability groups most commonly evoked by the term "handicapped" — usually accounted for less than six percent of the total special education population.

Such data indicate that classifying children depends on many factors, some of which are independent of the child's needs, such as economic conditions within the district. Some classifications — notably the "learning disabled" designation — may reflect the school's positive effort not to stigmatize children as mentally retarded or to provide some extra services for certain children as other sources of funding have been declining.

Classification of a child's primary handicap is important, because it is closely associated with —

but doesn't entirely determine — placement in the school and the related services provided. Placement is an individual matter. Although a child may share a similar handicap with other children, he may have it in a different degree, or he may have different academic capabilities and a different level of social functioning. Theoretically, placement reflects all these needs and capacities.

Children with the same classification, therefore, may be found in regular classrooms, in special classes within regular schools, or in separate special schools. (Figure 2) These choices depend on state requirements, local and state traditions, professional attitudes, availability of personnel, community policies, and interpretations of the law. Overall, in the five sites:

- 96 percent of the children receiving special education services attended regular schools;
- 25 percent spend their entire school day in a regular classroom;
- 33 percent were in a regular classroom for most of the school day, though they might be taken out for special services; and
- 38 percent were primarily in special classes, though some of them, too, might spend part of the day in a regular classroom.

Placements for children classified as having learning disabilities, emotional or behavioral disorders, or hearing impairments showed the largest variation across sites. For example, in Rochester, almost all learning disabled students were in special classes, while in Houston, most were in regular classrooms nearly full-time. Placement of children with physical, vision/hearing, or health impairments in particular was related to intellectual ability and academic performance. One of the barriers to regular placements for learning disabled or emotionally handicapped children was their social functioning, as well as their academic achievement.

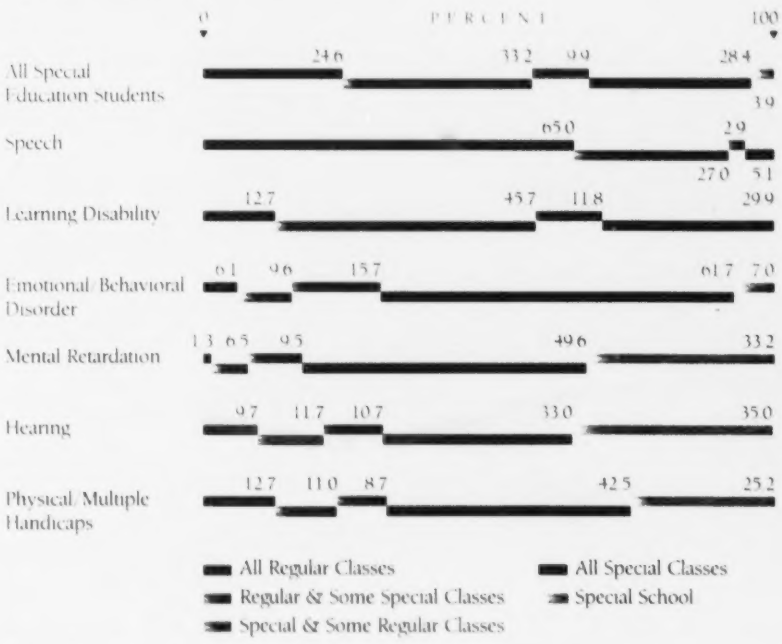
With so many special education children in the regular public schools, what does "regular" mean? In the five sites studied, the regular classes in which special education children were enrolled were similar in size and student composition to the average class in their school districts. Special classes were significantly smaller and more diverse in students' ages, grades, and handicaps. Classes in special schools were even smaller and more heterogeneous.

To accommodate special needs children, schools and classrooms have been tailored to individual students' requirements. Barrier-free access is commonplace, as are doorways, lavatories, cafeterias, and gymnasiums equipped to accommodate handicapped students. Elevators have been installed or modified for wheelchair accessibility. Non-skid surfaces have been laid down in school corridors and handrails mounted on walls. In one school studied, a "visual fire alarm" (a flashing light) was rigged for a deaf teacher. Each school offering the least restrictive environment to handicapped students is unique — the product of a determined director of special education, assisted by a committed and creative superintendent, board of education, principals, teachers, support staff, and parents.

No single best way exists for weaving educational goals and special services for handicapped children into the fabric of a traditional school system. Even within a single large district, a variety of experimental approaches may be tried. For example, in Houston, one school was attended solely by children at the two educational extremes — the severely and multiply handicapped and the intellectually gifted. The Charlotte-Mecklenburg schools clustered all hearing-impaired elementary students in one school, while schools on the district's geographic fringes served children with all other types of handicaps.

Nothing in PL 94-142 prescribes the schools' organizational arrangements, although many work through a combination of the efforts of the district-wide special education director and those of the

Figure 2. Placement by Classification



principals and teachers and staff who interact daily with the children and their parents. Clearly, there are many ways to meet the organizational challenge, to create the infrastructure of support, and to institutionalize the law's procedural guarantees, which were accompanied by important shifts in the school's attitudes regarding their responsibility toward disabled children. These are, perhaps, the law's most profound and lasting impact.

Family Environment

By and large, the proportion of minority students in special education was similar to their representation in the overall school population and reflected the local community. Minority groups accounted for more than a third of the special education population in the five study sites. In Houston, where many children did not speak English at home and problems with language contributed to speech and learning disabilities, minorities made up 77 percent of the special education group.

Boys predominated in special education, outnumbering girls approximately 2:1. Boys were most overrepresented among the speech impaired, learning disabled, emotionally disturbed, and mentally retarded.

Based on income levels and the percentage of families living in poverty at the time the study began, Rochester was the poorest district and Santa Clara County the wealthiest. Except in Santa Clara, more than 40 percent of the special education children were poor, having family incomes less than 150 percent of the federal poverty line. Among families with handicapped children in Rochester and Milwaukee, over half of the heads of household did not work; by comparison, 70 percent or more of heads of household in the other sites reportedly worked full-time.

The percentage of handicapped school children living with two parents ranged from 43 percent in Rochester to 76 percent in Santa Clara. In Houston and Rochester, fewer than half of the mothers of handicapped children had completed high school, whereas in Santa Clara more than 76 percent had.

Handicapped children from disadvantaged families and disadvantaged families coping with a handicapped child may need services and supports well beyond what the school can be expected to provide. The impact of PL 94-142 is bound to be lessened in states with weak Medicaid, mental health, and child service agencies; and the entitlement offered by the law will never be uniform across the states as long as these other variations persist.

Related Services

In addition to classroom instruction and individual supplementary instruction, when indicated, special education students receive a variety of related services through the schools — primarily speech therapy, physical and occupational therapy, and child counseling. However, the most costly supporting service is transportation. Students who need nursing care, recreational services, and even the full-time assistance of an aide may also receive these services. In 1984, the Charlotte district established a full-time physician's position to attend to the needs of multiply handicapped children during the school day, supplementing the school nursing staff.

Strong speech therapy programs existed in many schools prior to implementation of the federal law in 1977, and speech therapy remained widely available in the study sites with 46 percent of all special education students receiving some speech or hearing therapy. These services were targeted

Children like Matthew Bisson would probably be attending a special school were it not for programs mandated under P.L. 94-142. In special schools, physical therapy was frequently the primary focus with academics squeezed in. Because he attends a regular school, Matthew still has time set aside for P.T., but academics sets the tone.

primarily to children with speech disorders, hearing impairments, Down syndrome, and other forms of mental retardation; but many other children also worked with a speech therapist.

Physical and occupational therapy were provided to 74 percent of the children with physical or multiple impairments and 19 percent of the children with mental retardation; less than 10 percent of all other children received these services. Eligibility requirements for physical and occupational therapy were different in different districts, but those that limit these services to severely impaired children generally allowed more therapist visits.

Formal counseling services were targeted primarily to children classified as emotionally or behaviorally disturbed. Only about one-third of the total special education population received any kind of psychological counseling during the course of a year and usually only one or two sessions. Parent or family counseling was provided even less frequently and involved families of only 10 percent of all special education students. Yet 28 percent of the parents reported that their child's handicap had stressful effects on some important dimension of their lives, either on their ability to have or maintain child care, jobs, or friendships, or on their marriages.

The director of pupil services for one of the study sites attributes the shortage of counseling services directly to a lack of funds. According to her, state budget-cutting in the late 1970s meant that special education services "were cut to only 'mandated services' — virtually eliminating social workers and counselors."

The availability and role of social workers varied; but in addition to counseling children and families, they served as child advocates, arranged for respite care, provided liaison with and referral to community agencies, and when their personal style dictated and time and energy permitted, they developed extra-curricular programs for the handicapped children they served.

These related services are almost always paid for by school funds; in some sites, local health departments contribute to the program. Generally, related services, if provided by non-school employees, are arranged for informally and idiosyncratically, in order to avoid the inter-agency bureaucratic tangles that more formal arrangements might engender. Questions of payment and case management may or may not be well resolved, depending on the special education director's ability to work smoothly with health department, mental health, and other social service agencies' personnel.

Students qualifying for special education frequently need special transportation services, as well. In addition to conveying them between home and school, these services enable them to enjoy field trips and other educational or recreational activities along with their classmates.

Early Identification

Interviews with parents provided information on the age at which children's problems were identified and by whom. Fewer than 5 percent of all special education children were identified as disabled at birth. This small group tended to include the children with cerebral palsy, Down syndrome, and severe medical or neurological impairments — problems that are almost always identified by a physician or other health professional.

Within every handicap group, children diagnosed by physicans were identified, on average, two years earlier than children identified by non-physicians (usually school personnel). The age at which a child's problem was diagnosed was also associated with the mother's educational background — the better educated the mother, the earlier the problem was found.

While physical disorders and problems of vision and hearing tended to be noted well before school entry, 20 percent of the cases of mental retardation were not. Speech impairments, hyperactivity, and other developmental and learning disabilities — the "high-prevalence, low severity" disorders — were rarely noted before age three and some not until age 10.

Even if speech problems are identified early, nothing is usually done about them until a child enters school for any number of reasons. For example, many may be viewed as not serious, or parents may presume children will outgrow them.

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In the study, these problems were most likely to be identified by school staff during the first years of school.

Over the Years — Who Leaves and Who Stays?

Once children were recommended for special education, most continued to receive special services throughout their elementary school years. A study in the Charlotte, Milwaukee, and Rochester districts followed up children assigned to special education and found that 92 percent remained in their school district two years later. Of these, 71 percent were still in special education with the same classification, 12 percent stayed in special education with a different classification, and 17 percent were no longer receiving special education services. The children who had left public school were more apt to be hearing-impaired or physically handicapped with multiple other problems. They were also more likely to be white, from more affluent families, and more severely disabled than those who stayed.

Children in the speech-impaired group were the most likely to be reclassified, usually as learning disabled. Other students likely to change classification were those originally labeled physically or multiply impaired, most of whom subsequently were reclassified as mentally retarded. Disagreement between parent and school on a child's original classification was strongly associated with subsequent changes in classification.

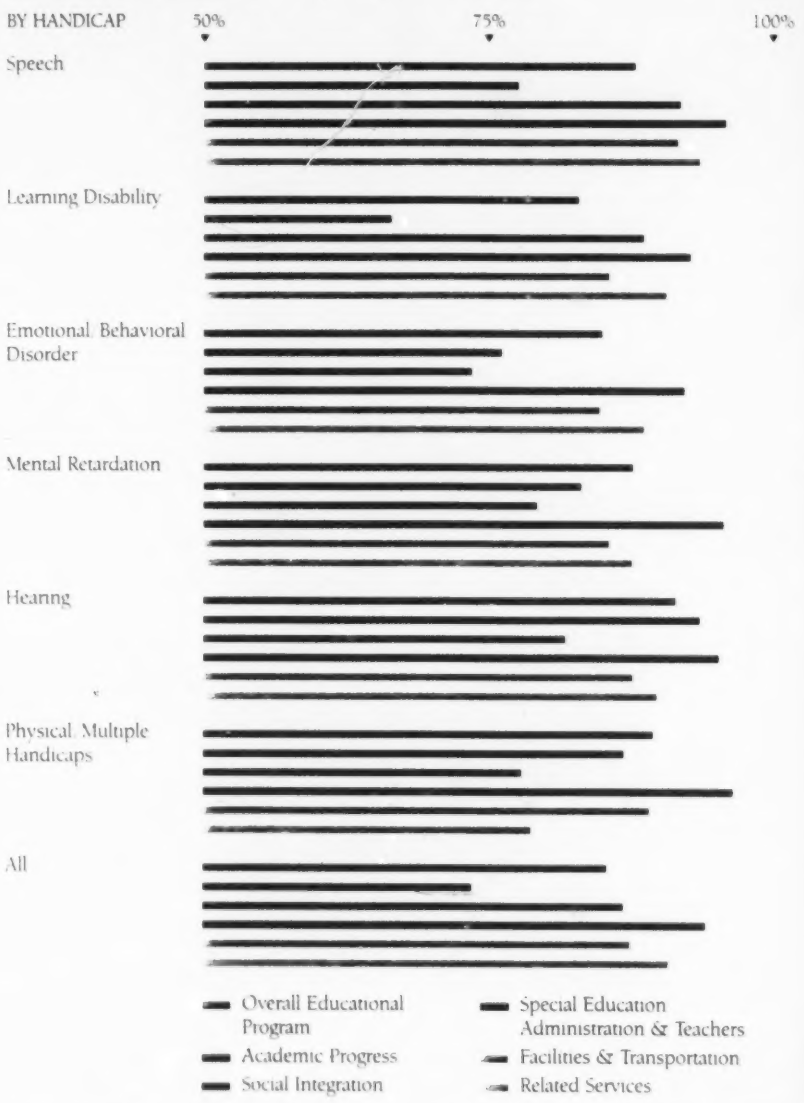
Within two years after the original data were collected, one-third of speech-impaired students at the three sites had been transferred out of special education. Unlike the speech-impaired students who were merely reclassified, those who graduated out of special education by and large were in the upper elementary grades, received only support services, and had no learning disabilities.

Special educators believe that many parents are reluctant to see their children transferred from special into regular education. Parents may have come to value the smaller groups and the individual attention and extra services their children receive and hesitate to give them up for the uncertainties of regular education.

Views of Parents and Teachers

At all five sites, parents were surveyed about their children's progress and whether or not they were pleased with the special education program. Teachers, too, were asked to comment on the progress of their handicapped students and on the effects of their presence on their non-handicapped schoolmates.

Figure 3. Parents' Satisfaction with Special Education Program



Regardless of site or family background, parents of special education students were generally very satisfied. They were satisfied with their children's overall education program and related services, with their social interaction with other students, with the administration and teaching in the special education program, and with the facilities. (Figure 3)

These findings are in marked contrast to parental views prior to the implementation of PL 94-142. In fact, the researchers believe that parents of special education students are more satisfied with the public schools than parents of school children in general.

Among some groups of parents, however, dissatisfaction was found. Many parents of children with learning disabilities were not happy with their children's academic progress, and many parents with intellectually normal, mobility-impaired children were not satisfied with their children's social integration.

Across all five sites, teachers were generally positive about the progress of students in special education, pointing to their improved academic performance, independence, social functioning, and general behavior as important indicators of their gains. (Figure 4) By spring, many more students reportedly were doing better in all four of these areas than were doing worse in even one. Children with emotional/behavior problems were reported by their teachers to have less improvement than any other group. This disturbing finding suggests the need for a substantial investment of attention to this group.[3]

Evidence on the effects of PL 94-142 on children's intellectual and social growth and development has been less clear. Because students are placed in classroom settings commensurate with their functional abilities, less impaired students are usually served in mainstream settings and more impaired students are usually served in separate settings. Although the researchers found that students placed in mostly regular classes did better in reading, mathematics, and social functioning than did their counterparts in special classes, they could not determine whether the differential was attributable to the setting or to these students' milder impairment to begin with.

Special Education Costs

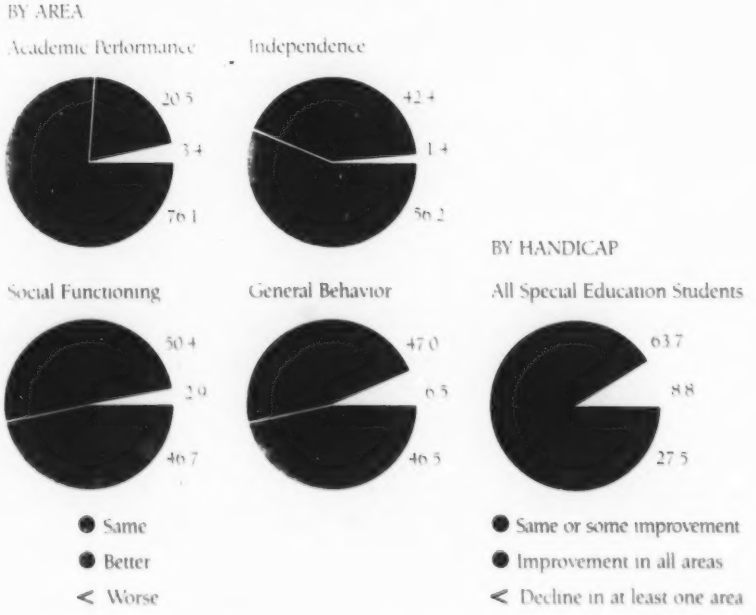
Since PL 94-142 was implemented in 1977, federal expenditures for special education have grown by 155 percent, to $1.16 billion in 1986. This contribution represents less than an estimated 12 percent of local school districts' special education costs.

In this study, costs of special education were studied in detail in the Charlotte, Milwaukee, and Rochester districts. These school districts spent nearly twice as much on the average special education student as on the average regular education student, even though per-pupil expenditures for individual special needs students varied greatly both across and within these districts. Average per-pupil expenditures in any given site reflected the mix of children, the number and type of educational resources provided, the cost of each unit of service, and placement.

In these three districts, the average annual cost was lowest for the speech-impaired student — in the low to mid-$5,000's in 1982-83, or about one-third more than the average for students without handicaps. Costs were somewhat higher for the learning disabled, emotionally/behaviorally disturbed, and mentally retarded. Collectively, children with physical, vision/hearing, or other health impairments were the most costly group and the group with the greatest variability in costs among individual children. For this group, the average cost per child was roughly twice that of the speech-impaired. Individual cases cost as much as $26,000 (in 1982-83 dollars), but these are very rare.

For every disability group in every study site, a full-time regular class placement was, on average, the least costly option. Thus, the "mainstreaming" ideology supports a least-cost approach and sometimes may be applied because of its economic rather than its educational benefits. Taking children out for additional instruction in a special class raises costs. Special classes, with or without some regular class instruction, are more expensive still.

Figure 4. Teachers' Report of Improvement During School Year (in %)

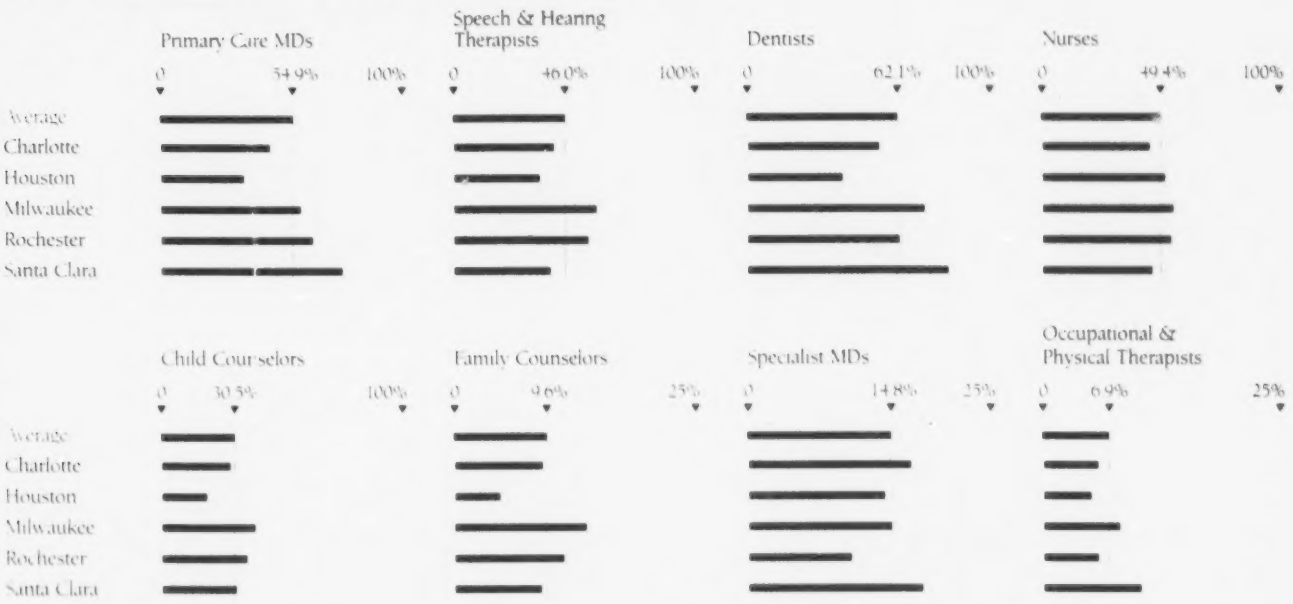


For all disability groups, instructional services were the largest single component of per-pupil expenditures, regardless of placement. Together, related services and indirect costs generally accounted for less than half of the total per-pupil expenditure.

It follows, then, that teachers' salaries remain a major determinant of per-pupil educational costs for the handicapped. Thus far, salaries for special education teachers have not posed an undue burden on school budgets relative to regular

3. The Robert Wood Johnson Foundation, in mid-1988, announced a new program for establishing and improving mental health services for children and youth, in large part because of the unmet need demonstrated by this study.

Figure 5. Special Education Students' Use of Health Services in the Previous Year



education salaries; but that is largely because salary differentials are based more on seniority than on special assignment or training.

However, today's school budgets are tightening, because enrollment is on the upswing. As indicated earlier, cost-cutting by eliminating or redeploying "non-essential" support personnel may not put the school district out of compliance with the law but may compromise the special education program's ability to serve children's multiple needs as defined by the law.

Health Care Access and Utilization

Although PL 94-142 neither mandates nor regulates health services for the handicapped, it assumes that children with educational handicaps deserve those health services that may enable them to benefit from their public education. Since The Robert Wood Johnson Foundation has traditionally focused on health care issues, the Foundation was interested in learning the extent to which public schools are facilitating improved access to health services for handicapped children and whether the health care sector was responsive to children's and school needs. Quite a few health-related services are used by special education students, again varying markedly by site. (Figure 5)

Physicians' involvement with handicapped children was looked at by the researchers with particular care. They found that medical examinations were rarely included as part of a child's school evaluation and were used mainly for children suspected of having mental retardation, neurological disorders, or general medical conditions. At one study site, for example, no medical evaluation was required for children suspected of an emotional/behavioral disability, some of which may have had a physiological basis. Physicians rarely attended IEP conferences, and, overall, physicians were in contact with the school in only 14 percent of all special education cases, mostly children with severe physical handicaps or chronic diseases.

Nevertheless, the American Academy of Pediatrics views medical input in the IEP as "essential not only to assist in making the diagnosis" for children with chronic disabilities "but also to help determine the most appropriate therapeutic measures."[4]

Teachers questioned during the study professed limited knowledge about the health status and medical management of children in their classes. Among teachers of children routinely on medication, half indicated they lacked a good understanding of the long-term health consequences of these children's disabilities, and fewer than one-third were familiar with the effects and side-effects of the medications. They reported that they were sometimes unaware of changes in

4. *Committee on Children with Disabilities. Pediatrician's Role in Development and Implementation of an Individual Education Plan.* Pediatrics 80(November): 750-751, 1987.

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prescriptions or dosages and did not know who was responsible for keeping them informed of such changes.

The health care needs of all children are diverse, and special education children were no different. Associated medical conditions were not uncommon. Children with cerebral palsy, other types of paralysis, epilepsy, or kidney disease used health services the most; but others, too, had serious health problems that required ongoing attention. Children with more than one health problem had at least four times the rate of hospitalization as children without health problems. For such children, access to medical care is central to progress.

Most children in the study had a regular source of health care — an encouraging finding since people who can identify a regular source of care are more apt to seek care in an appropriate and timely manner.[5] While overall only 7 percent of the study population had no regular source of care — roughly the national average — when looked at individually, the five study sites had between 2 and 15 percent of handicapped children with no regular source of care. Santa Clara and Rochester reported the highest percentage of children with a regular care source. Rochester was not an affluent community compared to other study districts, yet it had the greatest accessibility to public clinics and neighborhood health centers.

Although they may have had a regular source of care, only 74 percent of all handicapped students had a regular physician. Most commonly this was a pediatrician, but in many instances it was a general or family practitioner. Fewer than 10 percent of the regular physicians were specialists.

The rate of physician visits also varied widely by socioeconomic background and disability. Overall, 38 percent of the special education students across the five sites had not visited a physician in the year prior to the study; among the poor and among blacks and Hispanics, an even higher percentage reported no recent physician visit. The researchers attribute this finding to the persistent problems poor and minority families have in obtaining access to health services generally. Children with Down syndrome, vision and hearing problems, cerebral palsy, neurological disorders, or general medical problems were more likely to have seen a physician during the past year than were children with low-severity disorders.

Insurance coverage was associated with health services utilization, whether or not the child had a regular source of care or a regular physician. Twelve percent of the children in the study had no health insurance coverage at all, with substantial variation according to poverty, ethnicity, mother's education, and geographic location. For example, among children living in Houston (including significant numbers of Hispanics), more than 25 percent had no health insurance. In Santa Clara and Rochester, only 7 percent were uninsured. In Rochester and Milwaukee, most children were covered by public insurance; private coverage predominated at the other three sites.

Those with insurance were almost twice as likely to see a physician during the course of a year as those without it. Children with a regular source of care, a regular physician, and health insurance were nine times more likely to have seen a physician within the past year than were children who lacked these three.

Mobility-impaired children

In Houston, Milwaukee, and Santa Clara County, a special study was made of mobility-impaired children between ages 8 and 16, their parents, and their teachers. Mobility-impaired children are those who need wheelchairs, braces, or walkers in order to get around. These children were found in a wide variety of settings, depending on their intellectual ability, functional independence, and social behavior.

Parents of children who were mobility-impaired but intellectually normal were most satisfied if their children were in regular classrooms — especially if they were taken out for extra services. These children present the schools with one of their greatest challenges. Although they require a lot of costly physical support, they certainly can benefit from a rigorous academic program with other academically able children. Parents of children who were both intellectually and mobility-impaired generally preferred to have their children in a separate setting where they could receive services tailored to their individual needs.

Mobility-impaired children with normal intelligence were asked how they felt about themselves and what their aspirations were. Their self-esteem scores, impressively, were similar to those of other children, and their aspirations were high — reflecting a positive attitude toward the future.

5. *Butler JA, Starfield B and Stenmark S. Child Health Policy. In* Child Development Research and Social Policy *(Vol. 1) Stevenson HW and Siegel AE, Editors. Chicago: University of Chicago Press, 1984.*

Eligibility for public insurance differed among sites; but if a child was eligible, the scope of benefits was quite good — and generally better than private insurance which almost always required substantial out-of-pocket expenditures for certain components of care. Public insurance covered 82 percent of all costs associated with the eligible children's physician visits, whereas, one third of the parents with private insurance paid all of the costs of physician care. Even for children with severe disabilities, nearly one-quarter of the parents depending on private insurance had to pay their entire physician bill out-of-pocket.

The Individualized Education Program

At the core of PL 94-142 is the Individualized Education Program (IEP). Frequently inches thick and crammed with evaluation reports, test results, recommendations, and parent consent forms, each child's IEP folder contains a negotiated plan that is reviewed at least once a year. The plan is derived from a process by which all those who play a role in the child's educational, physical, and social development — including his parents — are brought together to share information and suggestions and to coordinate the school's efforts on his behalf.

The people who are to participate in the IEP are specified in the law as follows: the child's teacher, special education personnel (other than the teacher), one or both parents, and other individuals the parent or special education agency believes will add to the process. The law also allows for the child to attend when appropriate.

The individualized education program this group prepares must contain four components: a description of the child's present level of educational performance; a statement of instructional goals for the year, including short-term goals; a statement of the educational services the child will be provided and how much of the child's

Field trips enrich special education the same way they do regular education programs. Especially popular with the Milwaukee special education teachers are visits to Green Meadow Farms, where all children can experience the thrill of a pony ride or cuddling a kitten.

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Communicative Disorders in Children

In 1983, The Robert Wood Johnson Foundation awarded grants to five medical institutions across the country to provide coordinated care for children with communicative disorders. The program established model networks of coordinated screening, referral, diagnosis, intervention, and follow-up services for children at risk of functional disability due to hearing, speech, and language disorders. The projects were to integrate a screening and referral system into the primary care of these children. Each project explored ways in which primary care physicians could be encouraged and trained to identify, care for, and refer children for follow-up examinations.

Because so many special education children are speech-impaired or learning disabled, and because so much discussion has focused on the role of physicians in identifying communicative and other developmental disorders, some of the findings of the Communicative Disorders study bear mention within the context of this report on handicapped children.

Data from all five Communicative Disorders Program sites reveal that while physicians may support screening in theory, they rarely do it. The reasons for their reluctance are varied: (1) some of the available screening devices are cumbersome and time-consuming; (2) screening the total pediatric population results in a very few positive cases; (3) doctors believe that mothers will usually detect communications problems in their children and are not convinced that the information obtained through screening is useful for follow-up or remediation; and (4) the procedure is not currently reimbursable.

The program found that most screening in a health care setting is done routinely and well by trained nurses or speech and language specialists and that physicians are likely to get involved only when they are worried about a particular child. Therefore, the screening network might well be expanded to include day care centers, Head Start programs, and other settings in which young children are regularly found.

It concluded that the key time to screen is when a child is between 18 and 36 months of age, and the best way to begin is simply to ask the mother if she has any concerns about her child's speech or hearing. If the mother is concerned and the physician's initial assessment supports her concern, there should be follow-up with a valid screening instrument. For example, several projects in this Program used the Early Language Milestone profile. Any child who does not pass this screening test should be referred for more extensive evaluation and possible assistance.

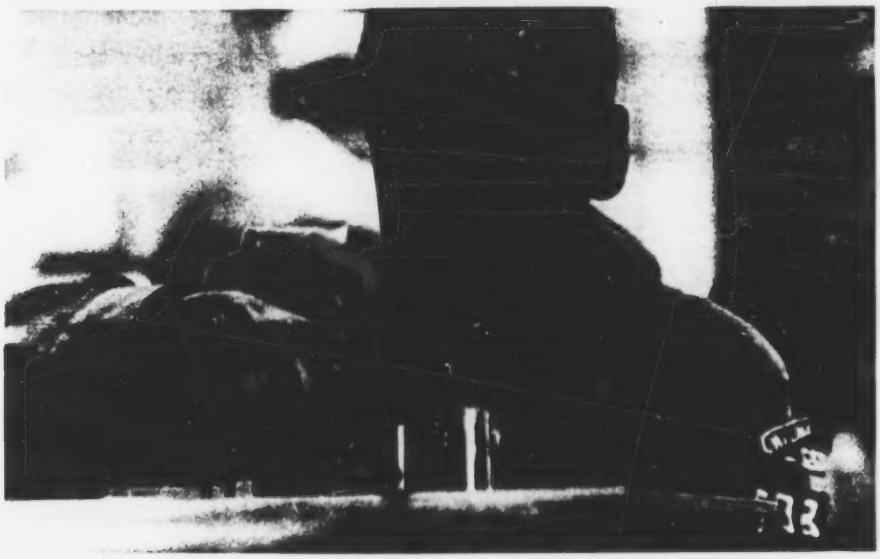
Of special note, any simple screening technique that can be administered in no more than one or two minutes and can easily be incorporated into a child's medical record has a good chance of being accepted and used by physicians. One participating project produced a set of rubber stamps, each with a few key developmental questions appropriate to a different age, which could be stamped directly into a child's medical record. This simple system met with a good physician response and was used.

The schools that received grants under the communicative disorders program were: the University of Colorado Health Sciences Center, the University of Iowa, the University of Medicine and Dentistry of New Jersey-Rutgers Medical School, Vanderbilt University School of Medicine, and the University of South Florida College of Medicine.

time will be spent in a regular classroom; and a specification of the duration of special services and the way they will be evaluated.

Sometimes the IEP process works exceptionally well. At one IEP conference observed for this report, eight participants gathered to review the problems, progress, and continuing educational needs of a youngster whose blindness was compounded by other related problems. The principal of his school, four of his teachers, one school-paid outside specialist, and his private speech therapist discussed with his mother in detail their plans for his school program the following year. This mother's active participation allowed a coordinated home-school-community program to be developed that greatly enhanced her child's educational opportunity.

Despite the importance of parental involvement, a disturbing finding of the study was that many parents did not attend yearly IEP conferences or become involved in the educational planning process. In all districts except Santa Clara, in fact, fewer than half of the parents attended their child's



A number of special education children were not handicapped at birth, but have suffered traumatic injuries during their childhood. Rozen King is re-learning basic skills that once were part of his everyday life.

most recent IEP.[6] According to several school principals, parents who failed to attend IEP meetings cited many reasons: work schedules, personal problems, lack of child care, no transportation. In one district, initial IEP conferences were scheduled in the home if that would enable parent participation. Some parents could not understand what they were told about their child's disorders, and some were intimidated by the process. Others' attitude was, "the school knows best," or they believed — rightly or wrongly — that their views would not count in the long run. And finally, there were parents who were simply burned out from endless coping with a handicapped child.

The unfinished agenda

This study has substantiated the enormous gains made in implementing the procedural protections of PL 94-142 — its social experiment aspects. However, several key areas of continuing concern are highlighted by the study and merit further intensive examination:

- Serious gaps still exist in services. Some children find themselves in a kind of "gray area" with respect to defining their problems and meeting their needs — for example, children with mild mental retardation, children whose emotional problems interfere with learning, and children whose language problems constitute a learning disability. Likewise, handicapped young adults, who may remain in the public school system until they reach age 21, rarely have access to services that will help them make the transition to adult life.
- Another challenge is serving the group of children who don't have access to school — very young children, children with such severe medical or emotional problems that they can't make it to school, post-secondary school-age children, and children with such severe behavioral problems that they can't be tolerated in the school environment. Revisions to PL 94-142 may ameliorate part of this problem by expanding services to preschool children.
- Families report encountering stress related to their child's handicap in the areas of work, housing, vacations, and friendships. The study documented the tremendous needs families have for respite care, day care, and summer camps for children with disabilities. Since families of children with disabilities often have additional social or economic problems, the schools cannot provide the entire service package that is necessary.
- The emphasis on the availability and use of services should not obscure concerns about the quality of these services, concerns that cannot be addressed without substantially more information about children's progress over time.
- Training for special education teachers and other personnel should reinforce the interpersonal aspects of working with handicapped children and their families. Teachers need to have available more resources such as paraprofessionals, volunteers, and itinerant teachers and to use parent support groups as a positive resource.
- Parents may need more help in becoming involved in the education of their handicapped children. A first step could be a careful

6. Singer JD and Butler JA. The Education for All Handicapped Children Act: Schools as Agents of Social Reform. Harvard Educational Review *57(May):125-152, 1987.*

examination of the barriers to getting greater parental participation in the IEP process. In many districts, advocacy groups have already made an important contribution.

Access to special education services does not guarantee better access to health care nor better cooperation between outside medical personnel and the schools. The study demonstrates that physicians rarely are involved with the schools in educational planning for their handicapped patients. Physicians need training in developmental benchmarks and diagnoses, beneficial programs and therapies for handicapped children, placement options in special education, and ways to assist families.

Clinics could do more to meet the needs of working parents and inform them about the importance of continuity of care. Health insurance plans need to provide better coverage of chronically disabled children, especially for some of the essential related services. Third-party reimbursements also could be structured to include incentives for closer physician-school cooperation.

In the United States, we have relied heavily on our public school systems as agents for social change with respect to handicapped children. Results of this major study underscore local school districts' positive response to far-reaching legislation for handicapped children, through their establishment and support for essential procedural guarantees. Nonetheless, maintaining and expanding the capacity of the public education system to serve handicapped children will depend on parents' continued vigilance and on the hard work of education and health professionals who design and implement programs addressing the day-to-day needs of individual children. Ongoing monitoring is essential to assure that the gains that have been made are not lost and that the remaining challenges — along with the inevitable new ones — are met.

Technical Appendix

The Collaborative Study used an identical design and methodology in all five participating school districts, enabling collection of detailed information on local special education policies, practices, and — to some extent — outcomes, as well as nationally relevant data. In each district, and at each stage of the study, personnel from the local special education program worked closely with project staff at The Children's Hospital of Boston to develop survey instruments, select a sample, obtain appropriate parental consents, and collect data.

Questionnaires were used to collect data on each student in the sample through interviews with parents, teachers, and physicians. Information from the student's record was also recorded.

The target population comprised all children in grades K-6 (or ages 5-13 in ungraded classes) who were in special education programs at the beginning of the 1982-83 school year and who were still in special education at the time interviews were held in the spring. To ensure adequate numbers of children with the more severe but less common problems, the sample was selected using a stratified random technique. Consequently, the study can reliably comment on the special education program's impact on children with less prevalent disabilities, as well as on the large group of speech-impaired and learning-disabled children who constitute the vast majority of special education students.

More than just classmates, children who are not impaired are gaining insight and sensitivity regarding the needs of their handicapped peers — qualities that cannot be learned from books alone and which they may carry with them into adulthood.

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